



BALANCE

Building Awareness Locally and Nationally through
Community Empowerment

Program for Diabetes •

Community Assessment Report 2000

MH07D7518



Association of Asian Pacific Community Health Organizations (AAPCHO)
1440 Broadway, Suite 510, Oakland, CA 94612
Phone: (510) 272-9536 Fax: (510) 272-0817 <http://www.aapcho.org>



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Staff

Jeffrey B. Caballero, MPH, Executive Director

Nina L. Agbayani, RN, Program Coordinator

Jacqueline A. Liro, Program Associate

Karen L. Yanagisako, MPH, Consultant



Collaborating Community Organizations

Advocate Initiatives for Grassroot Access, San Francisco, California

Chinatown Health Clinic, New York, New York

Family Health Center, Worcester, Massachusetts

International Community Health Services, Seattle, Washington

Kalihi-Palama Health Center, Honolulu, Hawaii

Kokua Kalihi Valley Health Center, Honolulu, Hawaii

Papa Ola Lokahi, Honolulu, Hawaii

South Asian Health Collaborative, Oakland, California

South Cove Community Health Center, Boston, Massachusetts

Waianae Coast Comprehensive Health Center, Waianae, Hawaii

Waimanalo Health Center, Waimanalo, Hawaii

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Foreword

Diabetes is the leading cause of adult blindness, end-stage kidney disease and lower limb amputations. This chronic disease is also one of the leading causes of death and disability in the US, and affects an estimated 16 million people, many of whom are Asian Americans and Pacific Islanders (AAPI's).

Diabetes has become a serious health problem in the AAPI community. Recent studies in Seattle and Hawaii indicate that in some AAPI sub-groups, the prevalence of type 2 diabetes is two to three times higher than in non-Hispanic whites. Thousands of AAPI's are suffering from the devastating effects of diabetes complications - adult blindness, kidney failure, lower limb amputations and an increased risk of heart disease and stroke.

An important step towards developing appropriate strategies to address diabetes in these communities is to include the active participation of people from the community. The Association of Asian Pacific Community Health Organization's (AAPCHO's) BALANCE Program for Diabetes, in collaboration with community organizations and individuals across the nation working with AAPI's, conducted community assessment activities from October 1999 through January 2000 in an effort to learn more about diabetes in AAPI communities. Community discussion groups were conducted with AAPI's living with diabetes and key informant interviews were conducted with community leaders and health care providers who serve AAPI's. The information collected from these activities is summarized in the BALANCE Program for Diabetes Community Assessment Report. It is a pleasure to present you with this document.

The report highlights common concerns and issues that may be used to develop more effective and appropriate diabetes education messages and programs to reach AAPI's. We hope that you will find the information interesting and useful. We encourage you to utilize the information in your capacity to increase awareness of diabetes in AAPI communities, improve the treatment and outcomes for AAPI's living with diabetes, promote early diagnosis, and ultimately, prevent the onset of diabetes. Together, we can reach this goal.

Jeffrey B. Caballero, MPH
Executive Director
Association of Asian Pacific Community Health Organizations



Introduction

The number of people living with diabetes has continued to increase significantly in the United States during the last half of the twentieth century.ⁱ This increasing burden from diabetes is mainly due to the increase in the number of people with type 2 diabetes. Though research examining the impact of diabetes on Asian Americans and Pacific Islanders (AAPI's) is limited, local community studies and surveys indicate that AAPI's such as Asian Indians, Chinese, Filipinos, Japanese, Koreans, Native Hawaiians, and Samoans are more adversely affected by the disease and its debilitating long-term complications than non-Hispanic whites, and their rates are significantly increasing.ⁱⁱ

Although improvements in blood glucose control have been shown to significantly decrease complications from diabetes,^{iii,iv} cultural and social barriers can often prevent these benefits from reaching minority populations. Adherence to some clinical models of diabetes treatment may not be compatible with cultural beliefs and practices. The successful management of lifestyle risk factors, such as promoting regular exercise and good eating habits, is at least as dependent on cultural beliefs and practices as it is on the recommendations made by health care providers.^{v,1}

The Association of Asian Pacific Community Health Organization's (AAPCHO) Building Awareness Locally and Nationally through Community Empowerment, or BALANCE Program for Diabetes, works cooperatively with the Centers for Disease Control and Prevention and the National Institutes of Health's National Diabetes Education Program (NDEP) to address the critical issues related to diabetes in AAPI's. From October 1999 through January 2000, the BALANCE Program conducted 13 community discussion groups (CDG's) with a total of 97 AAPI's living with diabetes and 36 key informant interviews with health care providers and community leaders. These community assessment activities took place in the states of California, Hawaii, Massachusetts, New York and Washington, at community health centers and agencies that serve significant populations of AAPI's. The CDG participants and the key informants were identified and recruited by staff of the collaborating community health centers and agencies.

The purpose of conducting the community assessment activities was to gather information on diabetes as it relates to AAPI's, assess the current level of understanding regarding diabetes and to collaborate with community representatives to ensure that the specific needs of AAPI's are identified and addressed in diabetes care. In planning, recruiting and conducting the

ⁱ A health care provider is an individual who provides health services that are accepted by the mainstream, or Western, medical establishment. Such individuals include physicians, registered nurses, dietitians, pharmacists, certified diabetes educators, ophthalmologists, optometrists, podiatrists, dentists and physical therapists.

CDG's, each site utilized community and cultural protocols specific to their population to ensure that their respective approaches were appropriate. Nine of the thirteen CDG's were conducted in a language other than English because it was the participants' primary language. These languages included Cambodian, Cantonese, Filipino, Korean, Pohnpeian, Samoan and Vietnamese. Since participants from the South Asian CDG's spoke several South Asian languages as well as English, English was used because it was the common language among the participants. In addition, the two CDG's with Native Hawaiian participants utilized "pidgin English," a local speech form used in Hawaii that combines English, Hawaiian and other AAPI languages.

This report includes the findings and recommendations based on the data collected, as well as the methodology and cultural protocols utilized in the community discussion groups and key informant interviews.



Method

The organizations selected to conduct the community assessment activities were community health centers and agencies across the nation that serve AAPI's. These organizations include: Advocate Initiatives for Grassroot Access, Chinatown Health Center, Family Health Center, International Community Health Services, Kalihi-Palama Health Center, Kokua Kalihi Valley Health Center, South Asian Health Collaborative, South Cove Community Health Center, Waianae Coast Comprehensive Health Center and Waimanalo Health Center.

In preparation for the community assessment activities, collaborating community organizations were provided with the BALANCE Program's "Community Assessment Guide" containing step-by-step information on how to conduct key informant interviews and community discussion groups. In addition, AAPCHO staff conducted a half-day workshop so that facilitators and recorders could become familiar with the process and review the CDG questions (See "Recruitment" in Cultural Protocols). In most cases, this workshop was provided within one week of the scheduled CDG. AAPCHO staff also provided technical assistance to the collaborating community organizations in planning, recruiting and conducting the CDG's.

Thirteen (13) CDG's were conducted with ninety-seven (97) people living with diabetes. The CDG's were ethnically specific and in most cases, the discussion was conducted in the participants' primary language. In Hawaii, five CDG's were conducted: a Filipino, Micronesian, two Native Hawaiian and a Samoan CDG. Three CDG's were conducted in Massachusetts: Cambodian, Chinese and Vietnamese. An additional Chinese CDG was conducted in New York and one Korean CDG was conducted in Washington. Three CDG's were conducted in California; one with Samoans, one with South Asian men and another with South Asian women.

A total of thirty-six (36) key informants were interviewed. A minimum of three (3) key informant interviews were expected to be conducted at each site, and only two sites interviewed less than three key informants. The key informants were either health care providers serving AAPI's or community leaders. In total, twenty-three (23) health care providers and thirteen (13) community leaders were interviewed as key informants.

The questions fell into the following categories: community problems, knowledge of diabetes, self-management of diabetes, culture and diabetes, services available and program planning. Responses from the CDG's were recorded on newsprint and audiotapes. The participants, with assistance from researchers when needed, completed background data sheets that provided individual demographic information. The researchers also completed a debriefing report immediately following each CDG. Researchers then transcribed the tapes verbatim and, in most cases, translated the transcripts into English. Data from the key informant interviews was recorded by the interviewer on interview forms, as well as on audiotapes.

The BALANCE Program utilized a data analysis strategy that incorporated transcript-based analysis, tape-based analysis and note-based analysis. Transcripts, data sheets, newsprint sheets, audiotapes and key informant interview forms were reviewed; participant responses were aggregated and categorized; and common themes were identified. These themes emerged consistently across questions, community discussion groups and key informant interviews. The themes are summarized and presented in this report and recommendations were developed to address the issues raised.





Findings

There were a total of 97 participants living with diabetes in the CDG's, 57 women and 40 men. The mean age of the women was 57.8. The mean age of the men was 59.1. Approximately 80% of the participants had family members with diabetes and on average, people reported 1.8 family members with diabetes.

There were a total of 36 key informants, 23 were health care providers and 13 were community leaders. Twenty-five of the key informants were women and 11 were men. Nine (25%) were living with diabetes and 26 (67%) reported having family members with diabetes.

Community Problems:

The top problems identified by the community discussion groups were and health problems, transportation, language barriers, nutrition and diet, and crime. The top community problems identified by the key informants were diabetes and health problems, alcohol and drug abuse, language barriers, lack of money and unemployment. Similarities among the top problems identified by both the community discussion groups and key informant interviews were diabetes and health problems, and language barriers. Interestingly, although nutrition and diet was a major concern of the community discussion group participants, only one key informant identified it as a major problem.

Knowledge of Diabetes:

In general, people understood which factors contributed to diabetes, but some misconceptions were identified such as "eating too much sweets," acquiring diabetes through blood transfusions and taking heart medication. Many participants sought medical attention and were diagnosed after exhibiting the signs and symptoms related to diabetes, such as weight loss, increased urination and fatigue. A few were diagnosed through a routine physical examination. Although they consider their medical doctor the primary authority in the management of their diabetes, many practice and consult with practitioners of complementary medicine.²

Self-Management of Diabetes:

Management strategies identified across the community discussion groups were diet, exercise, taking their medication regularly and stress reduction activities. There were many challenges that people with diabetes faced when managing their disease. In regards to diabetes management, the South Asian group said "Avoid three things: hurry, worry and curry," and mentioned culturally specific exercises such as yoga.

² Treatments or traditional health protection and restoration practices including Acupuncture, Ayurvedic medicine, faith healing, herbal and other treatments that have not been accepted by the mainstream, or Western, medical establishment.

"Good tasting food is one of life's great pleasures," (Cantonese, NY). Diet is the management strategy with which people with diabetes have the most difficulty. One of the reasons is the difficulty of changing their eating habits from their original ethnic diets to the western "healthy foods" recommended. "It is impossible to follow the diet recommended by nutritionists [such as eating]...raw carrots, cheese and milk," (Cantonese, NY). There was the perception that ethnic foods had to be given up in order to follow a healthy diet. Rice was mentioned as being an important part of people's diet and as being very difficult to give up. As one CDG participant emphatically stated, "We eat rice!" (Korean, WA). Another reason stated was that healthy foods were expensive. The Native Hawaiian groups acknowledged that convenience foods high in fat, such as fast foods from McDonald's, food from the manapua³ man and canned foods, are readily available and priced within their budget, making it difficult to maintain a healthy diet.

Exercise was also mentioned as being difficult for people with diabetes. Some of the reasons people chose not to exercise included: not enough time due to work schedules, the perception that exercise is for young people and not for the elderly, and lack of motivation. Reasons related to the lack of motivation included not wanting to exercise alone, being too tired or lazy, not having a plan, or not understanding how to exercise. The South Asian women stated, "the exercise needed to be something they could do in a sari."⁴

Taking medication regularly is difficult. This is mainly due to not having enough time, being too busy, frustration with taking the medication all the time and difficulty refilling prescriptions due to cost and lack of transportation. It was mentioned in the Honolulu Samoan CDG that people share their medication with people who do not have medication. This was also true of the participants from the Vietnamese community in Massachusetts. Having someone help administer medication, such as a family member or a nurse's aide, was mentioned as an alternative that would make it easier to take medication on a regular basis.

Visiting the doctor regularly is also a challenge. As stated in the above management strategies, lack of time due to work schedules is an issue. Lack of transportation, health insurance and money were also mentioned frequently. A few people described the wait in the doctor's office as being too long. Factors that made it easier to see a doctor regularly were having friendly, helpful staff and free transportation or living close enough to the clinic so that transportation is not a problem.

³ Chinese steamed bun filled with pork.

⁴ A South Asian woman's garment that consists of several yards of lightweight cloth draped so that one end forms a skirt and the other a head or shoulder covering.

Factors that help people better manage their diabetes included support from family members and others with diabetes. Health education from their health care provider was seen as essential. For some of the ethnic groups, women said they need support from men (e.g., South Asian women said it is easier to manage their diabetes "...if a man in the house has diabetes"). Taking herbal medicine was also mentioned as being helpful in managing diabetes.

Culture and Diabetes Care:

Many of the participants stressed that health care providers should be knowledgeable and respectful of the cultural practices and beliefs of AAPI consumers. It is important for health care providers to understand the eating habits and ethnic foods (e.g., that Filipinos eat "bagoong" or fish sauce) of their patients when recommending a healthy diet. Ethnic foods are usually not incorporated into recommended nutrition and diet making a "healthy diet" extremely difficult to maintain. Many foods identified in meal plans and in the food pyramid are not part of the AAPI diet. It was suggested that ethnic foods be included in nutritional counseling and meal plans. "We eat limu (seaweed), fish, taro, sweet potato and ulu (breadfruit)," (Native Hawaiians, HI). The South Asian group mentioned some of the spices they use in cooking which help with digestion, are turmeric, mustard and cumin. They also shared that fasting is a strategy they use in managing their diabetes.

The Samoan and Micronesian groups mentioned social gatherings as an important part of their culture. The "Fa'a Samoa" or Samoan customs related to the obligation a family has to the community to contribute and participate in social functions (weddings, funerals, celebrations) adds tremendous stress to an individual and his or her family, and can adversely affect their overall health. The abundance of food offered at social gatherings also makes it difficult to stick to a healthy diet because it is considered rude to refuse food. In the Samoan community, much of the families' free time evolves around church activities. It was noted that an abundance of food is served and physical activity is not incorporated into these church activities, making diabetes management difficult. In the Micronesian group, it was also mentioned that the large amounts of food available at parties are difficult to resist, and many of the foods are unhealthy.

Having a health care provider that acknowledges complementary medicine and spiritual practices are helpful. As one of the CDG participants shared, "We believe in a holistic approach to health, mental and physical well-being. Doctors focus only on physical aspects of well-being," (South Asian, CA).

Many individuals combine western and traditional remedies. Herbal ingredients that are commonly used by the Cantonese community in New York include lotus seed and wai san. Many Filipinos believe in faith healers, and will consult with them rather than seek treatment from a medical doctor. One commonly used remedy is a poultice⁵ obtained from a faith healer, which is applied to an affected area.

Services Provided:

Community health centers were identified as a service provided in their community. Services provided by these centers included primary care, dental, eye care, optometry, cardiology, laboratory services, nutrition programs, transportation, education, outreach, referrals for other services, support groups, translators, translated written materials, follow up, public health nurses, free medicine and blood glucose monitoring. It should be noted that most of the participants in the CDG's were patients of the community health centers, which may have influenced their responses.

Other services mentioned were yoga classes, meals on wheels, endocrinologists, public health nurses, health fairs, transportation, support groups and hospitals. Some focus groups responded that no services were available for people with diabetes in their community.

Services Used:

Available services that were utilized include services at the community health centers, transportation, health fairs, school health programs, community exercise programs, herbalists, outreach workers, university medical school services and hospitals. A factor contributing to service utilization was cost. If a service was free, it was utilized more frequently. The Micronesian and South Asian groups, who tend to travel back to their country of origin often, compared services there with services in the United States. The Micronesian group mentioned using medical services in the United States that accept health insurance from the Federated States of Micronesia.

Services Not Used:

Services that were not used included those that were not located in the community, were too expensive and those with which participants were unfamiliar. Lack of health insurance was also a factor that prevented many people from using services in their communities. Issues that made it difficult to obtain medical services included the long waiting period

⁵ A hot, moist mixture of leaves.

at the clinic or office to see a doctor, the lengthy procedure involved in scheduling appointments and the lack of interpreters.

Program Planning:

Participants' suggestions for an ideal or perfect program for people with diabetes, included "one-stop shopping" at clinics, doctor's offices that provide comprehensive care, nutrition programs that offer cooking demonstrations using ethnic foods, walking and exercise groups, exercise facilities, support groups for people with diabetes and their caregivers, and workshops on diet and nutrition. Other ideas included health care providers and educators from the community who understand the patient's culture and speak their language, positive role models with diabetes to share their success stories, accessible location and a program that is available during non-traditional hours so it is more accessible to working people.

Many participants mentioned the best way to inform people in the community about programs is through "word of mouth" by trusted channels (endorsement and explanation by credible community members). Other methods included advertising through ethnic and local media (radio, TV, print), outreach, churches and parish bulletins, websites, work places, employment and welfare offices, grocery stores, health fairs and free screenings. Stores frequently visited by members of the community (such as surf shops in Hawaii) and advertisements on Chinese videos at video stores were also mentioned as ways of informing the community about programs.

Communication was an important factor in motivating people to use services and programs. People were more likely to use services when information was provided clearly and in their language. Outreach workers and community "gate keepers" (ministers, traditional healers) of the community were identified as individuals that could help promote the program or messages. Free services and incentives are also ways of recruiting participants and encouraging families to get involved.

Overall:

The top community problems identified in the community discussion groups, with the exception of crime, were mentioned throughout most of the discussions in relation to diabetes management. The most challenging issues in diabetes management were nutrition, exercise, transportation and

receiving culturally and linguistically appropriate care. Work-related issues including busy schedules, lack of personal time and difficulty maintaining self-management strategies at work were frequently mentioned. In general, nutrition and exercise were strategies where people required more assistance. In particular, participants wanted nutritional information specific to their ethnic foods. With respect to physical activity, the most frequently mentioned form of exercise was walking, and most participants favored exercising in groups. Providing transportation to services and encouraging support from family members and others with diabetes were also key points that were mentioned. Participants also noted that the medical doctor is the primary authority they look to in managing their diabetes, and stressed that health care providers who are knowledgeable and respectful of their culture are essential to helping them manage their disease.



Recommendations

Overall:

- Acknowledge and address the critical need for ethnic-specific and culturally appropriate foods and nutritional information in diabetes care and education.
- Provide information about physical activity, encourage appropriate regular exercise in safe environments and empower people with diabetes to start their own exercise groups.
- Provide culturally and linguistically appropriate services for people with limited English proficiency, including oral and written materials in their primary language.
- Promote and encourage health care providers' understanding and respect for the cultural practices and beliefs of Asian Americans and Pacific Islanders.
- Consider the transportation needs of people in service delivery and program planning.
- Address issues related to work (busy schedules, difficulty maintaining self-management strategies during work, lack of personal time) in all aspects of diabetes care and education.

Knowledge of Diabetes:

- Reinforce and enhance the understanding of diabetes.
- Promote the recognition of risk factors, increase awareness of signs and symptoms of diabetes, and provide education on the complications of diabetes.
- Emphasize the importance of receiving regular medical care.
- Acknowledge patient beliefs and practices, and address myths and misconceptions about diabetes.
- Promote communication between health care providers and practitioners of complementary medicine.
- Increase health care providers' knowledge about complementary medicine.
- Promote communication between health care providers and patients regarding the use of complementary medicine.

Self-Management Strategies:

- Encourage family participation and support for managing diabetes, and stress that family involvement leads to healthy living for the entire family.
- Educate people with diabetes about the importance of Self Blood Glucose Monitoring (SBGM), and assure that equipment and supplies are accessible and affordable.
- Address people's fear of needles through the development of skills for SBGM.
- Educate nutritionists, people with diabetes and health educators about culturally appropriate, healthy, good-tasting, inexpensive food choices, and how to incorporate them into meal plans.
- Provide information about physical activity, encourage appropriate regular exercise in safe environments and empower people with diabetes to start their own exercise groups.
- Encourage diabetes education for employees, employers, managers and supervisors at worksites.
- Promote diabetes management strategies at work sites.
- Address long waiting periods for appointments at doctors' offices.
- Address transportation needs related to diabetes care.
- Provide a friendly clinic or office environment.
- Identify existing support groups in the community. If none are available, form support groups for people with diabetes and their families.
- Promote male support of women with diabetes in cultures where women's roles are subordinate to men.

Culture and Diabetes Care:

- Promote communication between health care providers and practitioners of complementary medicine.
- Increase health care providers' knowledge of complementary medicine.
- Promote communication between health care providers and patients regarding the use of complementary medicine.
- Provide culturally and linguistically appropriate services for people

with limited English proficiency, including oral and written materials in their primary language.

- Promote and encourage health care providers' understanding and respect for the cultural practices and beliefs of AAPI's.
- Develop culturally sensitive and individually tailored programs for the management of diabetes.

Things to Consider in Program Planning:

- Ensure that services are conveniently or centrally located in the community or provide transportation to services.
- Provide incentives and affordable services with scholarships to encourage participation.
- Provide services during non-traditional hours based on the target population.
- Provide information about physical activity, encourage appropriate regular exercise in safe environments and empower people with diabetes to start their own exercise groups.
- Provide services for people with limited English proficiency in their own language by qualified persons or according to state mandates.
- Provide nutrition workshops and cooking demonstrations that promote the inclusion of healthy ethnic foods.
- Identify existing support groups in the community. If none are available, form support groups for people with diabetes and their families.
- Actively involve community members in program planning, implementation and evaluation.
- Assess patients holistically and address their immediate needs (such as housing, food, clothing) while dealing with their diabetes.

Promoting Programs in the Community (recruitment):

- Work with trusted community members to recruit participants through one-on-one contact or word of mouth.
- Advertise strategically through ethnic and local media (radio, television, print).
- Advertise strategically at frequently visited community sites.



Cultural Protocols

In planning, recruiting and conducting the CDG's, each site incorporated community and cultural protocols to ensure that respective approaches were appropriate. This section of the report describes some of the methods used by participating sites.

Recruitment:

Facilitators and recorders were selected for specific reasons. Nine out of the thirteen CDG's included participants with limited English proficiency, so the facilitators and recorders chosen were bilingual and able to facilitate and record the discussion in the participants' primary language. These facilitators and recorders were often staff from the collaborating sites and/or credible members of the community. Some participants were familiar with the facilitators and recorders, which made participants feel more comfortable and at ease. Trust and confidence in the facilitators and recorders were crucial.

Participants were contacted and recruited using different methods. The staff from most of the sites had established relationships with the participants prior to the CDG. Some of the sites recruited patients from their centers and organizations through physicians' lists and diabetes support groups. The researchers noted that a trusted member of the community or a participant's doctor or nurse invited individuals to the CDG in-person or through phone calls. This was believed to be the most effective method of initial contact. To follow up on initial contact, phone calls and mailings were utilized. Some of the Micronesian participants did not have a phone at their homes, so relatives and friends were called and asked to relay the message to these individuals. Since Chinese newspapers serve as the primary source of information for the Chinese community in New York, advertisements were placed in these newspapers. It was also noted that because letters are impersonal, it was the least effective method of recruiting participants. Letters should only be used as a follow-up during the recruitment process. The South Asian participants were recruited during an Indo-American seniors' community event in which the staff from the collaborating health organization personally handed out fliers and made an announcement during the event. The staff also decided it was more appropriate to hold gender specific community discussion groups because participants would share their thoughts more openly.

Language:

As noted previously, nine out of the thirteen CDG's were conducted in the participants' primary language. These languages included: Cambodian,

Cantonese, Filipino, Korean, Pohnpeian, Samoan and Vietnamese. Since participants from the South Asian CDG spoke several South Asian languages as well as English, English was used because it was the common language shared by the participants. The two CDG's with Native Hawaiian participants used "pidgin English," a local speech form used in Hawaii that combines English, Hawaiian and other AAPI languages. Most of the CDG discussions were casual and relaxed, and respect was paid to elders throughout the discussion in manner and verbal communication. Since most of the participants in the Korean CDG were elders, the facilitator used a high level of formality when addressing the participants. In the Pohnpeian CDG, the facilitator apologized for not using the formal language because she was not fluent in that language. In addition, the facilitator knew that some of the participants did not speak the formal language, so she further explained that using the language common among participants would allow everyone to speak comfortably.

Food:

Food was served to make participants feel welcome and to give participants something to do while waiting for others to arrive. It was important to serve both culturally appropriate, as well as nutritious foods. Fruits, vegetables, salads, fruit juices and water are some of the examples of healthy items that were offered. Some of the ethnic foods served included "pansit" or noodles and "lumpia" or egg rolls at the Filipino CDG; "pakoras" or fried vegetables dipped in batter at the South Asian CDG; "congee" or rice porridge and steamed dumplings at the Chinese CDG's; and "kim-bop" or Korean sushi at the Korean CDG.

Most of the sites served the food before the CDG began and the food was made available throughout the meeting. A short introduction and prayer was shared before the food was served at the Samoan focus groups.

Time of Community Discussion Group:

In scheduling the time and day of the CDG, the most important factors considered were the work schedules and transportation needs of participants. Some of the CDG's were also scheduled around church activities and community center activities.

Honorarium:

Most of the sites chose to give stipends ranging from \$20.00 - \$60.00 to compensate participants for their time. For most of the CDG's, the hono-

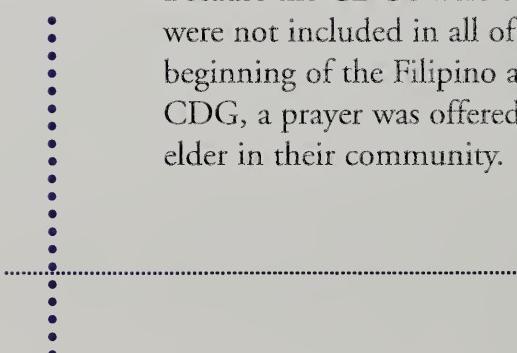
arium was an encouraging factor contributing to their participation. A gift certificate to a popular supermarket was given at one of the CDG's, as the high cost of food was a common complaint in that community. Of the sites that gave monetary gifts, only one site encountered a problem. One of the participants felt insulted by this gesture and the staff concluded that gift certificates might have worked better in that situation. In addition to the stipend, one of the sites raffled an additional gift as a fun way of thanking the participants for their participation.

Adjustments made to the Community Discussion Group process:

The responses from participants were written in the language that was spoken in the CDG on the newsprint charts (flipcharts) so that participants could read them. Forms were translated and provided in the appropriate language prior to the CDG so participants could read them, or they were translated during the CDG's by the facilitator. CDG's were located in meeting rooms at the community health centers or community halls, locations with which the participants were familiar and comfortable. Stand-up name cards were not used during some of the focus groups because this was thought to be inappropriate. In one case, a CDG was conducted without taking newsprint notes or audiotaping. The facilitator for this particular group felt that audiotaping the CDG and using the prepared newsprint to record the participants' responses as required by the CDG protocol would not be culturally appropriate for the participants in the community. In this case, the facilitator provided post-session notes written from memory (See *Lessons Learned*).

Opening and Closing of Community Discussion Group:

Because the CDG's were conducted informally, blessings and prayers were not included in all of the groups. A national greeting was said at the beginning of the Filipino and Vietnamese CDG's. At the Micronesian CDG, a prayer was offered by one of the participants who is a respected elder in their community.





Lessons Learned: Strengths and Challenges

The BAI.ANCE Program for Diabetes' community assessment activities included developing the "Community Assessment Guide," planning and conducting the thirteen community discussion groups (CDG's) and 36 key informant interviews, gathering, aggregating and analyzing the data, and writing the final report. In looking back over the process, researchers were satisfied with the overall design and outcomes of the project. Much of the success of this project was due to the hard work, commitment, receptivity and enthusiasm of the CDG participants, key informants, staff of the collaborating community health centers and agencies, facilitators and recorders.

In analyzing specific aspects that might have worked better, the first suggestion would be to add three months to the timeline to allow the researchers to work more comfortably. The original timeline developed in May 1999 called for the CDG's to be conducted from August through October 1999, with all the CDG and key informant data turned in to the researchers by November 11, 1999. However, the schedule was revised several times during the process to accommodate the need for additional time to prepare and conduct the CDG's and interviews, complete the transcript translations, and aggregate and analyze the data. The timeline was also adjusted to allow the researchers to be present at the majority of the CDG's, which took place at multiple locations across the country. In particular, inputting the data took much longer than originally anticipated.

Specific areas of the needs assessment process that the researchers would like to highlight are discussed below.

Workshop for Facilitators and Recorders

When researchers developed the first workshop to prepare facilitators for the CDG, recorders were not required to participate. However, once the first CDG was conducted, researchers realized that a formal training of the recorders was needed in order to sufficiently review all the newsprint charts and forms they would be using. Subsequently, recorders were asked to participate in the workshops.

The role-play portion of the workshop was probably the most helpful in preparing the facilitators and recorders for the CDG. Due to the amount of time scheduled for the workshop, it was not possible to role-play the entire script. In retrospect, role-playing the entire community discussion group script would ensure that facilitators and recorders understood all the questions, knew what kind of information the questions were intended to elicit and experienced a practice session of the CDG.

Community Discussion Groups (CDG's)

Letters of invitation confirming the CDG's were sent out to the participants in a timely manner for all but one of the CDG's. Confirmation letters reminded participants of the purpose, date, location and time of the CDG, and were written in English or the participants' primary language for those with limited English proficiency. In the one case where the letters were sent out late, participants did not receive them prior to the CDG and there was a misunderstanding about the location of the session. This caused the CDG to start a half hour late.

At several of the CDG's, participants asked their facilitator for information about diabetes. Since the CDG was not designed to answer participant questions about the disease, the facilitator was not able to address their questions. In future CDG's, it is recommended that an appropriate health professional be present to answer participants' questions at the end of the session. Even though the CDG was not intended to be an educational session, taking the opportunity to address the questions and concerns of people living with diabetes would be an appropriate health promotion strategy and consistent with the overall goals of the project.

Cultural Protocol

Incorporating cultural protocols into the CDG's was a clear strength of the overall process (see **Cultural Protocol**). Ensuring that approaches were culturally appropriate was critical to creating an environment that enabled participants to be candid, comfortable and receptive. In one case, however, the facilitators' commitment to cultural appropriateness resulted in a CDG where neither newsprint notes nor audiotapes captured the responses of the participants. The facilitator for this particular group felt that audiotaping the CDG and using the prepared newsprint to record the participants' responses as required by the CDG protocol, would not be culturally appropriate for the participants in this community. The only data provided from this CDG were post-session notes written from memory by the facilitator without any corroborating data. Fortunately, another CDG with participants representing the same ethnic group had been previously conducted and provided all three data collection methods. In the future, a CDG that compromises the data collection methods should not be conducted.

Community Discussion Group Script

Due to time constraints, a pilot test of the CDG script was not conducted.

Conducting one or two pilot tests prior to the first CDG would have been very helpful in identifying problematic questions. Time should also be allowed to revise the script between the pilot test and the implementation of the focus groups. Since the majority of CDG's were conducted in a language other than English, researchers were not aware that particular questions were unclear until the translated transcripts were provided several weeks after the CDG.

There were specific questions in the CDG script that were not clear to many participants and failed to elicit the information researchers hoped to obtain. For example:

Question 3: "How did you find out you had diabetes?" was confusing and did not evoke the responses the researchers were seeking. This question was included to find out what prompted the participants to see a doctor, i.e., what form of community awareness motivated them to find out that they had diabetes. Participants responded with the physical symptoms they had experienced before they were diagnosed, such as "changes in the body," "tired all the time," "blurry vision," rather than explaining how they learned that the symptoms could be related to diabetes, such as through information obtained from a friend, health fair, or media. Adding a probe to the question such as "What types of information, or who gave you the information that, led you to believe you might have diabetes" may have been clearer. This question should also have been included in the key informants' interview for comparability, and was not.

Question 4: "How do you think you got diabetes?" was also not included in the key informants' interview. A question such as "How do diabetes patients think they got diabetes?" should have been asked of key informants.

The number of questions that were included for the 1.5 hours allotted to the CDG was ambitious. The researchers accommodated the lack of time by prioritizing the self-management questions and then instructing the facilitators to ask only the top five. For future CDG's, either the number of questions needs to decrease or the amount of time allotted to conduct the CDG needs to increase.

Some of the questions seemed redundant although the intent was to obtain different information (Questions 8 and 9; and 11 and 15). Since there were too many questions for the amount of time allotted, some questions could be eliminated and facilitator probes added, to clarify the questions.

Question 8. We'd like to ask you how your culture affects how you take care of your diabetes. By "culture," we mean your daily practices or activities that come from your family's and community's beliefs."

Question 9. Are there factors in your culture that affect how you take care of your diabetes?

Question 11. Which of these services do you use? Why have you used that service?

Question 15. What was it about the services or programs to help manage your diabetes that motivated you to use them in the past?

Community Discussion Group "Background Information Sheet"

In the "Background Information Sheet," Question 7, "How long has it been since you last saw a doctor for your diabetes?" was unclear. Many participants interpreted this to mean, "How long has it been since you were diagnosed with diabetes?"

Data Collection

The importance of obtaining complete data cannot be overemphasized. In conducting the data analysis, the three sources of data, the newsprint notes, the audiotapes and the verbatim transcript of the audiotapes (translated into English for the CDG's that were conducted in the participants' primary language), were carefully reviewed, compared and analyzed. The three sources provided corroboration and explained data that was unclear. Of the thirteen CDG's, three sources of data were provided for all but three of the CDG's conducted.





Conclusion

This report is the collective contribution of AAPI's living with diabetes, community leaders, health care providers and organizations that serve AAPI's. A notable finding of the community assessment was the importance placed on ethnic communities' cultural practices, beliefs and history in the management of diabetes. "Because we don't understand or speak English, it has become a barrier to us to look for help" (Micronesian, HI). Identifying the most effective ways to overcome these barriers cannot be accomplished without input from the community. Culturally and linguistically appropriate approaches to all aspects of diabetes management must be emphasized.

The recommendations in this report were crafted to address the gaps and needs in diabetes care expressed by the participants of this community assessment. They are meant to be used as guides in the design, implementation and evaluation of diabetes programs for AAPI's. "When we get diabetes, we live with it for life. The good thing is that there are ways we can control diabetes" (Vietnamese, MA). It is AAPCHO's hope that these Asian and Pacific Islander voices will provide a foundation for developing more effective and appropriate diabetes education messages and programs for AAPI communities. AAPCHO also encourages incorporating ongoing feedback from consumers into diabetes programs and policies so that the community voices will continue to be heard. "Don't stop here. Continue on," (Samoan, HI).



Appendix A

Community Discussion Group Questions for People With Diabetes

1. We'd like to get an idea about what you feel are the major problems in your community. What do you think are the top five problems in your community?

2. Where would you put diabetes in relationship to the problems listed here? Please explain.

3. How did you find out you had diabetes?

4. How do you think you got diabetes?

5. Let's talk about some things people can do to manage their diabetes? What do you know you should do help manage your diabetes?

6. We are going to discuss some of the things the American Diabetes Association recommends that people with diabetes do. As you will see, many of the items you've mentioned fall into these categories.

* We would like to learn what makes it hard or easy for people with diabetes to do these things? So for the first item listed, which is ___, what are some of the things you feel make it hard or easy to do this? (Repeat this question until all of the following items are covered).

a. Test their own blood for glucose levels regularly

b. Follow a healthy diet

c. Exercise regularly

d. Take their medication correctly

e. See the doctor regularly

f. Quit smoking

g. Don't drink alcohol

h. Check their feet every day

i. See the dentist every year

j. Get their blood pressure checked regularly

k. Get their eyes checked every year for diabetes (Facilitator: Explain that this is for a "dilated eye exam," not for eyeglasses.)

7. What helps you manage your diabetes?

8. We'd like to ask you how your culture affects how you take care of your diabetes. By "culture," we mean your daily practices or activities that come from your family's/community's beliefs. What would you like your health care provider (doctor, nurse, nutritionist, etc.) to know/understand about your culture?
9. Are there factors in your culture that affect how you take care of your diabetes?
10. What services are available for people with diabetes in your community?
11. Which of these services do you use? Why have you used that service?
12. Which of these services have you not used? What haven't you used them?
13. Imagine an ideal/perfect program for diabetes in your community. Please describe this program.
14. What would be the best way to inform people in the community about this program?
15. How would we get people to use this program?
16. We're almost at a close. Is there anything else anyone would like to say? Any last thoughts about this?

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Appendix B

Key Informant Questions for Community Leaders

1. How long have you lived in this community?
2. How would you describe your role in this community?
3. With which culture or ethnic group do you most identify?

| | | |
|---------------------------------------|--|-------------------------------------|
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Hmong | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Japanese | <input type="checkbox"/> Palauan |
| <input type="checkbox"/> Burmese | <input type="checkbox"/> Kapingamiragi | <input type="checkbox"/> Pohnpein |
| <input type="checkbox"/> Caucasian | <input type="checkbox"/> Khmer (Cambodian) | <input type="checkbox"/> Samoan |
| <input type="checkbox"/> Chamorro | <input type="checkbox"/> Korean | <input type="checkbox"/> Sri Lankan |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Kosraean | <input type="checkbox"/> Tahitian |
| <input type="checkbox"/> Chuukese | <input type="checkbox"/> Laotian | <input type="checkbox"/> Thai |
| <input type="checkbox"/> Fijian | <input type="checkbox"/> Marshall Islander | <input type="checkbox"/> Tongan |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Mien | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Hawaiian | <input type="checkbox"/> Nepalese | <input type="checkbox"/> Yapese |
| <input type="checkbox"/> Other _____ | | |

4. What do you feel are the top 5 problems in your community?
5. Turning to diabetes, is it a problem in your community? Compared to the other problems mentioned, how important is diabetes? Please explain.
6. Do you have diabetes?
7. Do any of your family members have diabetes?
8. I'm going to go over some things people can do to prevent or manage diabetes. I'll ask you how "easy" or "hard" you think each one is for people with diabetes. Please explain why?
 - a. Test their own blood for glucose levels regularly?
 - b. Follow a healthy diet?
 - c. Exercise regularly?

- d. Take their medication regularly?
 - e. See the doctor regularly?
 - f. Quit smoking?
 - g. Don't drink alcohol
 - h. Check their feet every day
 - i. See the dentist every year
 - j. Get their blood pressure checked regularly?
 - k. What else is important? Why?
9. I'd like to ask you how you think culture affects the way people in your community take care of their diabetes. By "culture," we mean their daily practices or activities that come from their family's/community's beliefs.
- a. From your experience with _____ (insert ethnic group of community), what do you think health care providers (doctor, nurse, nutritionist, etc.) should know/understand about this particular culture?
10. Now, I'd like to ask you about the services in your community.
- a. What services are available for people with diabetes in your community?
 - b. Which of these services do people use? Why?
 - c. Which of these services are not used? Why?
 - d. What services could be improved or added?
11. Imagine an ideal/perfect program for diabetes in your community.
- a. Please describe this program.
 - b. What agency/group could develop this program?
 - c. Who could be involved?
 - d. What would be the best way to inform people in the community about this program?
 - e. How could we get people to use this program?
12. What do you think is the best way to provide education about diabetes to Asian American and Pacific Islander patients in your community?
13. We're almost through with the interview. Is there anything else you would like to add?



Appendix C

Key Informant Questions for Service Providers

1. Where are you employed?
2. What is your job title?
3. What are your job duties/responsibilities?
4. How long have you worked at the organization where you are employed?
5. How long have you worked in this community?
6. How long have you worked with Asian American and Pacific Islanders?
7. With which culture or ethnic group do you most identify?

| | | |
|---------------------------------------|--|-------------------------------------|
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Hmong | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Japanese | <input type="checkbox"/> Palauan |
| <input type="checkbox"/> Burmese | <input type="checkbox"/> Kapingamiragi | <input type="checkbox"/> Pohnpein |
| <input type="checkbox"/> Caucasian | <input type="checkbox"/> Khmer (Cambodian) | <input type="checkbox"/> Samoan |
| <input type="checkbox"/> Chamorro | <input type="checkbox"/> Korean | <input type="checkbox"/> Sri Lankan |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Kosraean | <input type="checkbox"/> Tahitian |
| <input type="checkbox"/> Chuukese | <input type="checkbox"/> Laotian | <input type="checkbox"/> Thai |
| <input type="checkbox"/> Fijian | <input type="checkbox"/> Marshall Islander | <input type="checkbox"/> Tongan |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Mien | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Hawaiian | <input type="checkbox"/> Nepalese | <input type="checkbox"/> Yapese |
| <input type="checkbox"/> Other _____ | | |

8. What do you feel are the top 5 problems in your community?
9. Turning to diabetes, is it a problem in your community? Compared to the other problems mentioned, how important is diabetes? Please explain.
10. Do you have diabetes?

11. Do any of your family members have diabetes?
12. I'm going to go over some things people can do to prevent or manage diabetes. I'll ask you how "easy" or "hard" you think each one is for people with diabetes. Why?
 - a. Test their own blood glucose levels regularly
 - b. Follow a healthy diet?
 - c. Exercise regularly?
 - d. Take their medication correctly?
 - e. See the doctor regularly?
 - f. Quit smoking?
 - g. Don't drink alcohol?
 - h. Check their feet every day?
 - i. See the dentist every year
 - j. Check their blood pressure regularly?
 - k. What else is important? Why?
13. I'd like to ask you how you think culture affects the way people in your community take care of their diabetes. By "culture," we mean their daily practices or activities that come from their family's or community's beliefs.

From your experience with _____
(insert ethnic group or community), what do you think health care providers should know or understand about this particular culture?
14. Now, I'd like to ask you about the services in your community.
 - a. What services does your clinic provide to people with diabetes?
 - b. What services are available for people with diabetes in your community?
 - c. Which of these services do people use? Why?
 - d. Which of these services are not used? Why?
 - e. What services could be improved or added?

15. Imagine an ideal/perfect program for diabetes in your community.
 - a. Please describe this program.
 - b. What agency/group could develop this program?
 - c. Who could be involved?
 - d. What would be the best way to inform people in the community about this program?
 - e. How could we get people to use this program?
16. What do you think is the best way to provide education about diabetes to Asian American and Pacific Islander patients in your community?
17. We're almost through with the interview. Is there anything else you would like to add?

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